Final Report

Ryan White Title I
HIV Health Services
Planning Council

Comprehensive Needs Assessment
of the
Phoenix Eligible Metropolitan Area
2002

Language, Culture, and Health Institute

August 1, 2002

Acknowledgements

We would like to thank the Planning Council's Needs Assessment Workgroup for overseeing the needs assessment and their significant contribution to the success of this process. Their suggestions, recommendations, and positive energy were extremely valuable in keeping us motivated. We value and respect their commitment to persons living with HIV/AIDS.

In addition, the following agencies and their administrators and staff members were invaluable in their contribution to this endeavor:

AIDS Project Arizona
American Academy of HIV Medicine
Arizona Department of Health Services
Body Positive
HIV Care Directions
Chicanos Por La Causa
Ebony House, Inc.
Maricopa County Department of Public Health
Maricopa County Integrated Health System
McDowell Health Care Center
MOSAIC
Phoenix Children's Hospital
Phoenix Shanti Group
Pinal County Department of Public Health
TERROS, Inc.

Lastly, we would like to express our most sincere appreciation to the Ryan White consumers who took the time to participate in the focus groups, completed the surveys, and insisted that their voices be heard.

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I. Executive Summary

The scope of this assessment includes an update of the epidemiological profile from 2000 to 2001. This report will help to establish service priorities and planning for a continuum of care by documenting need for specific services.

The primary focus of this needs assessment is on people living with HIV/AIDS who are in and out of care. Primary data sources included a survey of persons with HIV disease, provider interviews, consumer interviews, and interviews with community members. Secondary data sources included epidemiological data from the Arizona Department of Health Services, socio-demographic data, client utilization data from Title II and Title IV providers, and data provided from McDowell Clinic, a primary provider of health services for people living with HIV/AIDS.

This assessment documents the following findings relative to HIV/AIDS prevalence:

- African Americans continue to be disproportionately represented in the cumulative HIV population in relation to their percent of total Maricopa County population. In Maricopa County African Americans account for 11% of the cumulative HIV cases, and 15% of the new HIV cases reported in 2001 although they make up only 3.7% of the population. Eight percent (8%) of the total number of HIV cases in Pinal County are among African Americans, although African Americans make up only 2.8% of the total population. This finding is consistent with the needs assessment conducted by the African American Capacity Building Coalition (Reilly, 2001).

- Latinos represent 16% of the total HIV population in Maricopa County, but account for 21% of the new HIV cases this year.

- Native Americans account for 2% of the cumulative HIV cases, which is in proportion to their representation in Maricopa County. However, this year 3% of the new HIV cases were among Native Americans.

- Asian/Pacific Islanders were proportionately represented in both the cumulative and new HIV cases, accounting for only 1% of the cumulative HIV population.

- Whites represent over 66% of cumulative HIV cases, with 58% of new cases reported among Whites in Maricopa County.

- The prevalence of HIV among women is still comparatively low in comparison to men. Men comprise 87% of the cumulative HIV cases and 87% of new cases in Maricopa County, while women make up 12.5% of cumulative cases and 12% of new cases reported in 2001.

- Men continued to be disproportionately represented in the total HIV population, at 87%.

This assessment also documents reasons why people living with HIV/AIDS do not seek medical care. Reasons given include apathy, legal status, depression, medical limitations and cultural and linguistic limitations. These responses were collected through surveys and interviews with consumers and providers. This data gathering approach considered socio-economic factors, geographic access, health status, age, and gender.

This assessment also addresses service gaps and unmet needs among subpopulations. This determination consisted of quantitative and qualitative information from multiple sources. However, this method does not take into account treatment provided by private doctors and unreported cases. As part of quantifying the unconnected, current Ryan White consumers were invited to participate along with friends and relations receiving or lacking medical care. These interviews covered sexual orientation, basic demographic, cultural and linguistic characteristics, health status, barriers to care, and most importantly experiences in seeking medical care.

As a final note, this assessment includes recommendations to address unmet need and improve overall access to care and service delivery to people living with HIV/AIDS.

II. Epidemiological Profile of HIV/AIDS in the Phoenix EMA

A. Introduction

HIV/AIDS affects every community in the state of Arizona, yet each community is impacted differently depending on individual risk behaviors, community norms, and variations in demographics (e.g. population trends, age of residents). Differences in geographic location, access to transportation, availability of health services, and access to insurance among current consumers are also factors that impact the delivery of primary health care services to persons living with HIV/AIDS (PLWHA) in the Phoenix Eligible Metropolitan Area [EMA]. Certain risk-taking behaviors are inextricably linked to a range of underlying community and societal factors as well as community norms and cultural values (e.g. " I am not likely to contract HIV", or "I don't want to be tested for fear I have HIV"). All of these risk factors in the absence of significant protective factors contribute to the perpetuation of the current HIV/AIDS epidemic. Consequently, the HIV/AIDS related service needs of the Phoenix EMA are multifaceted, and no single indicator may fully capture the multiple factors at work within the community.

In order to assess the complexity of needs within the Phoenix EMA (covering Maricopa and Pinal Counties), a multidimensional assessment framework has been applied to identify the relevant social and cultural factors that create potential barriers to services for populations with special needs living with HIV/AIDS. Based on available data, the extent of unmet health care needs among current consumers will be discussed. Finally, an estimate of the number of individuals who are aware of their HIV+ status, but are not accessing primary care services will be made based on their sub-population group membership.

Quantitative analysis of existing epidemiological and surveillance data from a variety of sources was combined with ethnographic methods (i.e., focus groups of consumers/providers and a survey of consumers of primary care services) to interpret data. It is anticipated that the obtained results will lead to an effective continuum of care for PLWHA and will yield outcomes that will have relevance for the community of PLWHA.

B. Epidemiological Profile of Maricopa County

Arizona ranked second to Nevada in terms of its overall population increase (percent change) between 1990-2000. In 2005, Arizona is projected to rank sixth in net population growth. These projections suggest a steady trajectory of increased population growth in the state. Maricopa County, as the largest county in the state, comprises approximately 60% of the total population of the state of Arizona. Based on the most recent US Census Bureau projections (from April 2000 to July 1, 2000) Maricopa County was ranked as the largest and fastest growing county in the US

with a population increase of 4.0% (up 122,649 to a projected 3,194,798 from April 2000). Maricopa County outstripped other large urban counties including LA County in California, Cook County in Illinois, and Harris County in Texas.

Maricopa County's rapid growth patterns also reflect significant increases among foreign-born people of color populations. The most significant increase among people of color populations is among Latinos. Between 1990-2000, the Latino population in Maricopa County increased by 120.9%, and the Asian population by 95.2% (U.S. Census, Department of Commerce, 2000). Foreign-born populations accounted for approximately 16% of the documented population increase in Maricopa County (Center for Immigration Studies, October 2001).

Figure 1: US Census 2000 Current Population of Maricopa County

	Maricopa County 2000 Census Data	**% of Total Maricopa County Population**
Ethnicity		
Latino	763,341	24.8%
Not Latino	2,308,808	75.2%
Race		
White	2,376,359	77.4%
Black/African American	114,551	3.7%
American Indian /Alaskan Native	56,706	1.8%
Asian	66,445	2.2%
Other Pacific Islander	4,406	0.1%
Other/Two or more races	453,682	14.8%
Total	**3,072,149**	**100%**
Gender		
Male	1,535,676	50%
Female	1,536,473	50%
Total	**3,072,149**	**100%**

1. HIV/AIDS Prevalence Estimates

HIV and AIDS surveillance data needs to be considered together to understand the scope of the HIV/AIDS epidemic in the Phoenix EMA. AIDS surveillance data, presented in Figure 3 is important in assessing access to care for different populations, but it does not reliably reflect trends in HIV transmission. Therefore,

HIV surveillance data is presented in Figure 2 because it is a more reliable indicator of future trends among specific populations in the Phoenix EMA.

Figure 2: Estimated Prevalence of HIV in Maricopa County by Race/Ethnicity/Gender

	% of Total Maricopa County Population	**# of New HIV Cases** (Through December 31, 2001[1])	**% of New HIV Cases in Maricopa County**	**# of Cumulative HIV Cases** (Through December 31, 2001[2])	**% of Total Maricopa County HIV Population** 2001	**Estimated Prevalence Rate Per 100,000**
Race/Ethnicity						
Latino	24.8%	85	21%	594	16%	77.8/100,000
White	77.4%	225	58%	2429	66%	102.2/100,000
Black /African American	3.7%	60	15%	417	11%	364/100,000
American Indian /Alaskan Native	1.8%	12	3%	89	2%	156/100,000
Asian	2.2%	4	1%	23	1%	41/100,000
Other	14.9%	1	<1%	146	4%	31.9/100,000
Gender						
Male	50%	340	87%	3235	87%	211/100,000
Female	50%	47	12%	463	13%	30/100,000

(*Source: AZ Statewide Coordinated Statement of Need: 2001)
(**[2]**Source: Maricopa County HIV/AIDS Surveillance Report, Arizona Department of Health Services, January, 2002.)

Figure 3: Estimated Prevalence Rate of AIDS in Maricopa County by Race/Ethnicity/Gender

	% of Total Maricopa County Population	**# of New AIDS Cases** (Through December 31, 2001[1])	**% of New AIDS Cases in Maricopa County**	**# of Cumulative AIDS Cases** (1986 through December 1, 2001[2])	**% of Total Maricopa County AIDS Population** 2001	**Estimated Prevalence Rate Per 100,000**
Race/Ethnicity						
Latino	24.8%	86	25%	849	16%	111/100,000
White	77.4%	194	56%	4001	74%	168/100,000
Black /African American	3.7%	40	11%	435	8%	379/100,000
American Indian /Alaskan Native	1.8%	16	<2%	115	2%	202/100,000
Asian	2.2%	4	<1%	29	<1%	52/100,000
Other	14.9%	-	-	4	<1%	<1/100,000
Gender						
Male	50%	295	86%	4967	92%	324/100,000
Female	50%	46	13%	457	8%	30/100,000

([1]Source: 2001 Joint Statement of the AZ Department of Health Service Plan in Cooperation with Statewide Planners)
([2]Source: Maricopa County HIV/AIDS Surveillance Report, Arizona Department of Health Services, January 2002.)

2. HIV by Subpopulation in Maricopa County

The numbers presented below represent a minimum estimate of HIV infections. Factors, including underreporting of HIV infections, and delays in reported cases should be considered when interpreting this data. In addition, this surveillance data does ***not*** clearly paint an entire picture of infection rates because anonymous positive test results are not included in this data. For example, from January 2000 to December 2001, there were 264 additional anonymous HIV positive test results in Maricopa County. Because this number is not calculated in surveillance data, it is difficult to assess the needs of this cohort.

Surveillance data reported is also limited in that it only documents the number of individuals who were initially reported and confirmed in the state of Arizona. Based on the results of the consumer survey, **nearly 28% initially tested positive outside of Maricopa or Pinal County**. This is another factor that would contribute to an underestimation of the current HIV population in the EMA.

a. Race/Ethnicity

Figure 4: Cumulative HIV Distribution by Ethnicity Through December 2001

Race/Ethnicity	Adult/ Adolescent Cases	%	Pediatric Cases	%	Total Cases	%
White, Not Latino	2429	66	14	55	2443	66
Black, Not Latino	417	11	5	20	422	11
Latino	594	16	5	20	599	16
Asian, Pacific Islander	23	1	0	0	23	1
Native American	89	2	1	4	90	2
Unknown	146	4	0	0	146	4
Total	**3698**	**100**	**25**	**100**	**3723**	**100**

b. Age

Figure 5: Cumulative HIV Distribution by Age through December 2001

Age	Cases	%
Under 5	20	1
5-12	4	1
13-19	67	2
20-29	1331	36
30-39	1499	40
40-49	582	16
Over 49	190	5
Unknown	30	1
Total	**3723**	**100**

c. Exposure Category by Gender

Figure 6: Cumulative HIV Distribution by Adult/Adolescent Exposure Category by Gender Through December 2001

Exposure Category	Males	%*	Females	%	Total
Men who have sex with men	1908	72	0	0	1908
Injecting drug users	322	12	129	28	451
Men who have sex with men and inject drugs	291	11	0		291
Hemophiliac	21	1	0	0	21
Heterosexual contact with a high risk individual	80	3	188	41	268
Transfusion with blood or blood products	24	1	14	3	38
None of the above/unknown	589		132	29	721
Total exposure cases	**3235**	**87**	**463**	**13**	**3698**

(*Percentages excludes data with missing or unknown data)

d. Mortality Rates

Figure 7: HIV/Related Mortality Surveillance Report-January 1, 2002

HIV Cases	Cases-HIV	Deaths-HIV
Maricopa	3723	201

Summary-HIV

- African Americans continue to be disproportionately represented in the cumulative HIV population in relation to their percent of total Maricopa County population. In Maricopa County, African Americans account for 11% of the cumulative HIV cases, and 15% of the new HIV cases reported in 2001. Similarly, African Americans PLWH are over represented in relation to their percentage in the general population, with an estimated prevalence of 364/100,000.

- Latinos represent 16% of the total HIV population in Maricopa County, but this year this group accounted for 21% of the new HIV cases.

- Native Americans accounted for 2% of the cumulative HIV cases, which is in proportion to their representation in Maricopa County. However, this year 3% of the new HIV cases were among Native Americans.

- Asian/Pacific Islanders were proportionately represented in both the cumulative and new HIV cases, accounting for only 1% of the cumulative HIV population.

- Whites represent 66% of cumulative HIV cases, with 58% of new cases reported among Whites in Maricopa County.

- The prevalence of HIV among women is still comparatively low in comparison to men. Men comprise 87% of the cumulative HIV cases and 87% of new cases in Maricopa County, while women claim 12.5% of cumulative cases and 12% of new cases reported in 2001.

- Men continued to be disproportionately represented in the total HIV population, at 87%.

3. AIDS by Subpopulation in Maricopa County

a. Race/Ethnicity

Figure 8: Cumulative AIDS Distribution by Ethnicity through December 2001

Race/Ethnicity	Adult/ Adolescent Cases	%	Pediatric Cases	%	Total Cases	%
White, Not Latino	4001	74	11	55	4012	74
Black, Not Latino	435	8	7	20	442	8
Latino	849	16	7	20	856	16
Asian, Pacific Islander	29	<1	0	0	29	<1
Native American	115	2	0	4	115	2
Unknown	4	<1	0	0	4	<1
Total	**5433**	**100**	**25**	**100**	**5458**	**100**

b. Age

Figure 9: Cumulative AIDS Distribution by Age through December 2001

Age	Cases	%
Under 5	16	<1
5-12	9	<1
13-19	26	<1
20-29	987	18
30-39	2516	46
40-49	1339	25
Over 49	565	10
Total	**5458**	**100**

c. Exposure Category by Gender

Figure 10: Cumulative AIDS Distribution by Adult/Adolescent Exposure Category by Gender Through December 2001

Exposure Category	Males	%	Females	%	Total
Men who have sex with men	3424	69	0		3424
Injecting drug users	427	9	161	35	588
Men who have sex with men and inject drugs	577	12	0		577
Hemophiliac	41	1	1	<1	42
Heterosexual contact with a high risk individual	126	3	170	37	296
Transfusion with blood or blood products	62	1	42	9	104
Confirmed occupational exposure	0	0	1	<1	1
None of the above/unknown	319	6	82	18	401
Total adult exposure cases	**4976**	**92**	**457**	**100**	**5433**

d. Mortality Rates

Figure 11: AIDS Related Mortality Surveillance Report-January 1, 2002

AIDS Cases	Cases-AIDS	Deaths-AIDS
Maricopa	5458	2993

Summary-AIDS

- In Maricopa County AIDS also disproportionately impacts African Americans, although the rate of infection is considerably lower than the national average for this population. In Maricopa County, African Americans represented only 3% of the total population but 8% cumulative AIDS population. African Americans accounted for 11% of the new AIDS cases reported in 2001.

- Latinos comprised 24% of the total population of Maricopa County population and accounted for 25% of the new AIDS infections reported in 2001 and 25% of cumulative AIDS cases.

- The percentage of Native Americans who comprised 2% of the total population of Maricopa County and accounted for 2% of new AIDS cases and 2% of cumulative AIDS cases.

- Whites continued to account for the majority of reported AIDS cases, representing 56% of new cases in 2001, and 73% of the cumulative AIDS cases.

- Women accounted for 8% of the cumulative AIDS cases, but among new cases in 2001 there was a notable increase in women's representation at 13%.

- Men continued to account for the majority of new and cumulative AIDS cases. Men accounted for 86% of new cases, and 91% of total AIDS cases in Maricopa County.

C. Epidemiological Profile of Pinal County

From a field of 100 fastest growing counties, Pinal County ranked 91st, posting a population increase of 5.1% (up 9,919 people from 179,727 in April 2000 to 188,846 in 2001). Figure 12 depicts the population distributions by race/ethnicity/gender of Pinal County.

During this same time period in Pinal County, the Asian population increased by 145.4% and the Latino population increased by 57.6%. The population of people of Latino is projected to comprise a substantially large share of the total population in all geographic regions of the country by 2050 (U.S. Census, Department of Commerce, 2000). Latinos accounted for 6% of the population increase reported in Pinal County (US Census, 2000). The largest majority of these legal immigrants were from Mexico (Center for Immigration Studies, October 2001).

Figure 12: US Census 2000 Current Population of Pinal County

	Pinal County 2000 Census Data	**% of Total Pinal County Population**
Ethnicity		
Latino	53,671	29.9%
Not Latino	126,056	70.1%
Race		
White	126,559	70.4%
Black/African American	4,958	2.8%
American Indian	14,034	7.8%
Asian	1,086	0.6%
Other Pacific Islander	146	0.1%
Other/Two or more races	32,944	18.3%
Total	**179,727**	**100%**

(Source: US Census, 2000)

1. HIV in Pinal County

a. Race/Ethnicity/Gender

Figure 13: Distribution of Cumulative HIV Cases in Pinal County by Race/Ethnicity/Gender through December 2001

	# of Cumulative HIV Cases (1986- Dec. 1 2001*)	**Estimated Prevalence Rate Per 100,000**
Race/Ethnicity		
Latino	28	52.2/100,000
White	41	32.4/100,000
Black/African American	8	161.4/100,000
American Indian	7	49.9/100,000
Asian	0	0
Other	8	24.3/100,000
Gender		
Male	77	
Female	15	

(Source: Pinal County Department of Public Health 7/13/2002)

Additional breakdown and distribution by exposure category and age was not available for Pinal County.

b. Mortality

Figure 14: HIV/Related Mortality

HIV Cases	**Cases-HIV**	**Deaths-HIV**
Pinal	84	6

(Source: Maricopa County HIV/AIDS Surveillance Report, Arizona Department of Health Services, January 2002)

2. AIDS by Subpopulation in Pinal County

a. Race/Ethnicity/Gender

Figure 15: Distribution of Cumulative AIDS Cases by Race/Ethnicity/Gender in Pinal County through December 2001

	# of Cumulative AIDS Cases (1986- Dec. 1 2001)	**Estimated Prevalence Rate Per 100,000**
Race/Ethnicity		
Latino	38	70.8/100,000
White	79	62.4/100,000
Black/African American	17	342.8/100,000
American Indian	7	49.9/100,000
Asian	0	0
Unknown	1	0
Total	**142**	
Gender		
Male	122	
Female	20	

Additional breakdown of data by exposure category and age was not available for Pinal County.

b. Mortality Rates

Figure 16: AIDS Related Mortality Surveillance Report-January 1, 2002

AIDS Cases	**Cases-AIDS**	**Deaths-AIDS**
Pinal	136	58

Summary

- In Pinal County, African Americans are also over-represented, accounting for 11.8% of the total AIDS population in the county.

- In Pinal County, Latinos accounted for 30% of the total HIV population, the largest percentage among people of color.

- Women in Pinal County represent a greater percentage of the total HIV population at 13.9%. This finding may suggest an increase rate of HIV in Pinal County.

- In Pinal County, where Native Americans represent over 7% of the population, only 4% of AIDS cases were reported in this group. This percentage exceeds the reported national prevalence for this population of 1%.

D. Socio-Cultural Risk Factors Unique to the Phoenix EMA That Impact Service Delivery

In the US, AIDS related deaths have had the greatest impact on young and middle age adults, particularly racial and ethnic minorities. While the number of people dying from AIDS nationwide has declined as a result of drug therapies, the increasing numbers of people living with HIV and AIDS highlights the need for more comprehensive HIV/AIDS health care services. A recent analysis of trends nationwide indicates that the number of new infections among urban gay men is rapidly increasing. Nationwide annually, about 4.4% of all young gay and bisexual men are newly infected and there is a rise in other STD's in this same group. The reported new infection rate among urban young gay men is now as high as it was at the peak in the mid 1980's.

Furthermore, the dramatic rise in new infections is disproportionately impacting men of color (Centers for Disease Control, Morbidity and Mortality Weekly Report, June 1, 2001). In a recent study based on survey data from seven cities (Baltimore, Dallas, Los Angeles, Miami, New York, San Francisco and Seattle) alarming numbers of new infections and overall infection rates in young gay men were reported:

Figure 17: HIV in US Cities-New/Overall Infection Rates Among Gay Men Age 15-22

Race/Ethnicity	**New Infections**		**Overall Infections**	
	94-98	**99-00**	**94-98**	**99-00**
Black	4.0%	14.7%	14.1%	30%
Latino	1.8%	3.5%	6.9%	15%
White	2.4%	2.5%	3.3%	7.0%

(Source: Centers for Disease Control, Morbidity and Mortality Weekly Report, June 1, 2001)

While the sample size of this study was small and not representative of all gay men, the results when combined with other data, including data from Maricopa County, points to a clear trend of increasing new HIV infections among men of color.

In Arizona, HIV/AIDS has already disproportionately impacted Maricopa County. With 60% of the states total population, Maricopa County claims 70% of all reported AIDS cases, and 72% of reported HIV cases. In the Phoenix EMA, the most frequently occurring age range for a diagnosis of AIDS was between 30-39 for AIDS and between 30-39 and 20-29 for HIV (AZ Department of Health Services, HIV/AIDS Surveillance Report, January, 2002).

Along with population growth, dramatic shifts in immigration patterns also need to be considered as part of the demographic picture of the State and of the Phoenix EMA. The 2000 Census found that 48.4% of Arizona's foreign-born population arrived in the state since 1990. Between 1990-2000 the percentage of "non-English speakers at home" increased from 20.8% to 25.9%. Arizona also has a naturalization rate of 29.6%, one of the lowest in the country, and lower than the national average of 40.1 %. This lower rate may reflect the fact that a large number of new immigrants are not yet eligible for naturalization, or it could reflect a larger number of undocumented immigrants (FAIR-http://www.fairus.org).

Using apprehensions at the border as a minimal estimation of population flow between the two countries, an estimated 387,406 illegal entrants were apprehended during FY98. This number has continued to climb due to a surge in illegal entry through Arizona as other sections (El Paso and San Diego) have gained better deterrence. The actual number of illegal entrants residing and in need of HIV related services are difficult to detect and determine, but must be taken into consideration. McDowell Clinic figures indicate that presently, approximately 117 undocumented citizens receive services. Among this population, access to primary medical care is negatively affected by the fear of apprehension and deportation.

Given Mexico's close proximity to the US border, future planning must take into consideration the impact of permeable borders between the US and Mexico on this epidemic of HIV/AIDS. Sex between men continues to drive Mexico's HIV epidemic. At the end of 1999, it was estimated that there were approximately 6 infected men for every infected woman. More recently, health officials in California and Mexico reported "alarming HIV infection rates among gay and bisexual men moving across the border " (Perlman, 2002). While prevalence rates among adults is still comparatively low (.28%), among men ages 24-44 in Mexico, AIDS is the third most common cause of death (U.S. Census, 2000). Mexico also lacks access to education and testing resources that would facilitate prevention and treatment.

The lack of health care coverage is another factor that impacts service delivery, and has been previously reported as a reason why some PLWH are not in care (ASU Needs Assessment, 2000). Based on nationwide trends, the number of uninsured rises to 21 % when non-elderly persons (under 64) are considered. Those most likely to be without insurance are adults ages 18-34; the age at which most individuals, particularly men are most likely to become HIV positive. In general,

women are more likely to have insurance than men, but their coverage is less stable than men whose coverage is often linked to employment.

Access to insurance is a major issue across the county, and the quality and length of life are distinctly different for insured and uninsured populations. Previous studies have shown that for PLWHA a regular source of medical care is critical to successful treatment of HIV/AIDS. A new report from the Institute of Medicine of the National Academy of Sciences states that uninsured, HIV positive adults are less likely to receive newer antiretroviral therapies, and even when they do, they wait longer than consumers with private insurance (CDC, 2002)

In one of the few studies of health coverage of persons with HIV-related disease, Schur & Berk (1994) found that 53% of respondents reported public coverage, Medicare or Medicaid, for their medical care. Another 28% were covered by private insurance, and 19 % had no source of payment. Presently, public health insurance programs pay for almost half of the medical care for people with HIV/AIDS in the US through Medicare, Medicaid, or a combination of both programs. In 2000, the Medicare program spent almost two billion dollars on HIV/AIDS care, or 28% of its funding. Medicare coverage expanded to include 37% of persons who were diagnosed but asymptomatic, and 50% of persons who were symptomatic but non-AIDS. Medicare covered a record 62% of persons living with AIDS.

The numbers of people living with HIV/AIDS who are dually eligible for both programs will continue to increase as people are living longer due to new life sustaining medications. Therefore, access to health care services that includes pharmaceutical coverage is critical. However, based on current population trends the gap between those who can access certain services and those who can not will continue to increase and will disproportionately impact the growing number of people of color, particularly Latinos (AIDS Action, April 2001-Medicare matters for people living with HIV/AIDS). Mohr (1994) found that traditionally disadvantaged groups differed from other groups in terms of the types of health care services used. HIV-infected minorities, injecting drug users, persons in the lower income category, and the unemployed appeared to use services on an emergency basis. In contrast, White persons, and those in the highest income category were more likely than others to report a visit to a private physician's office.

The lack of health care coverage has previously been identified as one of the many barriers facing all subpopulations of PLWHA in the Phoenix EMA area (Needs Assessment, 2000, ASU). In addition the current survey found that Spanish-speaking PLWHA deemed lack of services in Spanish a significant barrier to primary care services. Meeting the primary health care needs for PLWHA in care and not in care continues to be a major concern given the number of uninsured in Arizona. Eighteen percent (18%) of Arizonans are uninsured compared to the

national average of 12% (Kaiser Family Foundation, 2000 State Health Facts Online).

Lack of insurance has been correlated with poverty. Two-thirds of the uninsured have a household income less than twice the federal poverty income level. Although Medicaid insured 12.4 million poor people, 9.2 million still had no health insurance in 2000 (U.S. Census Bureau, Health Insurance Coverage, 2000). Nationwide, Latinos (68%) were less likely than White non-Latinos (90.3%) to be covered by health insurance. Native Americans are also less likely to be insured than Asians and Pacific Islanders or African Americans. The foreign born population was less likely than the native population to be insured and non-citizen immigrants accounted for fewer than 1/5 of the uninsured.

In Maricopa County, US Census data indicates that 12.7% of the population lives at or below the Federal Poverty Level. In Pinal County, the number living in poverty is substantially higher at 20.7%. Recent changes in income eligibility guidelines for Ryan White services will impact this population currently receiving services. Eligibility guidelines have been changed from 300% of the Federal Poverty Level to 200% of the Federal Poverty Level.

The poverty rate among children in both counties is also of concern. In Pinal County the number of children living in poverty is 27.9%, which is higher than the state average of 23.2%. In Maricopa County, 19.1% of children are living in poverty. Poverty among children and families often sets in motion a trajectory that increases the likelihood of other risk factors including homelessness, domestic violence, substance abuse, depression is likely to lead to decreased opportunities for protective variables like education (McLoyd, 2000). These factors are also often present among those least likely to be receiving services.

The impact of poverty is also more significant for certain subgroups. African Americans are disproportionately represented among those in deep poverty, and the impact of this risk factor is additive, contributing to other related factors like substance abuse. For example, African American women accounted for 41% of AIDS cases caused by injection drug use. Injection drug use has fueled the spread of heterosexual transmission, particularly among women. Transmission of HIV/AIDS related to substance abuse is a significant problem among all racial/ethnic minorities. Other co-morbid risk factors including mental illness, homelessness, poverty, and substance abuse are often present among those most in need of services, but least connected to formal support systems. All of these factors must be considered in defining the extent of unmet need in the Phoenix EMA.

For people of color seeking health care services for HIV/AIDS, the challenge of navigating the many systems of care to meet their health needs is daunting, particularly if their primary language is not English and they are undocumented. The

significant increase in the Latino populations in Maricopa and Pinal Counties will place increased demands on service agencies to provide services to Spanish speaking PLWHA. In addition, the combination of these socio-demographic factors unique to the Phoenix EMA would indicate that the demand for primary medical care and other related services supplied by culturally and linguistically competent providers for persons living with HIV/AIDS (PLWHA) is likely to increase. The number of persons who are unconnected from services will also continue to rise unless substantial decreases in the rate of poverty among children and people of color occur, and/or if increased opportunities to protective factors like health care and education are made available.

III. Assessment of Service Needs

A. Methodology

The primary focus of this needs assessment was on PLWH who are in and out of care. Primary data sources included PLWH survey (see Appendix A1 and A2), service provider interviews (see Appendix B1 and B2), consumers, and interviews with community members. Secondary data sources included epidemiological data from the Arizona Department of Health Services, socio-demographic data, client utilization data from Title II and Title IV providers, and data provided from McDowell Clinic, a primary provider of health services for PLWHA.

1. Consumer Surveys

The Language, Culture and Health Institute's needs assessment team developed the survey instrument, which was piloted with two consumers before being introduced to the sample population. The draft instrument was shared with the Planning Council committee overseeing the needs assessment. Questions on the survey were aimed at developing a demographic profile of current consumers and were designed to uncover unmet needs and barriers to access among those in and out of care. Questions were selected from a variety of existing measures and tailored to address the needs of the Phoenix EMA subpopulations. The survey included closed and open-ended questions. The survey was also translated into Spanish so monolingual Spanish-speaking individuals could participate. Clear instructions were developed so that there would be consistency in the administration of the surveys and the language was not too complex for consumers. Participation in the survey was voluntary and participants were assured of confidentiality. A stratified convenience sample was utilized, with particular attention given to people of color and women, subpopulations that are often disconnected from services. Target sub-populations included the following:

- Men who have sex with men
- Women of child bearing age
- Injection Drug Users
- Substance Abusers (other than injection drug users)
- Adolescents (13-19)
- African Americans
- Latinos/Latino's
- Native Americans

Women and Latinos were over-sampled in the sample of 227 people. Seventy percent (70%) of the sample was PLWH and 29% were PLWA. Figure 18 below compares the survey sample with the HIV population in the Phoenix EMA, along with the representation of targeted groups in the general population.

Figure 18: Consumer Respondents in Relation to HIV and General Populations in Phoenix EMA

Race/Ethnicity	Number in Survey (Total=223)	% Representation in Survey	% Representation among HIV population in Phoenix EMA	% Representation Among General Population Phoenix EMA
Latino	62	27%	16%	24%
White	132	59%	66%	77%
Black/African American	23	10%	11%	3.7%
Native American	5	2%	2%	1.8%
Asian	1	<1%	1%	1.8%
Gender				
Male	166	74%	87%	50%
Female	55	24%	12.5%	50%
Transgender	2	<1%	<1%	<1%

Virtually all agencies providing HIV/AIDS services expressed a willingness to distribute copies of the surveys. Agencies and their consumer groups who actively participated in the distribution and collection of surveys were are specified by parentheses below:

AIDS Project Arizona (Café Canela, Ladybug)
Body Positive
HIV Care Directions
Chicanos Por La Causa (Latino Mix)
Joshua Tree
Mc Dowell Clinic
Phoenix Shanti Group
Catholic Social Services

2. Provider Interviews

A comprehensive questionnaire was developed for service providers. This instrument was also shared with the Planning Council committee overseeing the needs assessment. A separate questionnaire was developed for the McDowell Clinic, which handles the majority of HIV/AIDS consumers in the Phoenix EMA. Separate interviews were held with each agency, and responses were categorized and summarized below. Agency administration, outreach staff, and case managers were interviewed in groups. Agencies interviewed included:

AIDS Project Arizona
Body Positive
HIV Care Directions
Chicanos Por La Causa
Ebony House

Maricopa Integrated Health Systems (Sandra Norman)
McDowell Clinic
MOSAIC
Pinal County Department of Public Health
Phoenix Children's Hospital
Phoenix Shanti Group
TERROS, Inc.

3. Consumer Focus Groups

A number of focus group sessions were held during the period between May 30 and July 1, 2002. Some groups were conducted in Spanish, and transportation and food were offered at some sessions. Several agencies assisted in developing and scheduling consumer focus groups:

- HIV Care Directions, AIDS Project Arizona, and Catholic Social Services collaborated to bring together a focus group of Latinos.

- HIV Care Directions staff brought together a group of women concerned about services.

- Phoenix Shanti Group staff arranged for participation by a client support group.

IV. Summary and Results of Consumer Surveys by Subpopulations

A. Consumer Survey

The following summary will highlight significant findings about barriers to primary care as they pertain to specific sub-populations. Appendix C includes a series of charts that depict the distribution of total responses to key items on the Consumer Questionnaire. In addition, responses are broken down by subpopulation.

1. Demographic Characteristics

The sample consisted of 75% men, 24% women and, <1% transgender. Fifty-seven percent (57%) of the sample described their sexual orientation as gay or lesbian. Thirty three percent (36%) described their sexual orientation as heterosexual. The heterosexual population was made up of the following:

White Women=21
White Men=12
African American Women=6
African American Men=7
Latino Females=17 (7 Spanish Dominant)
Latino Males=18 (15 Spanish Dominant)

People of color made up 59% of the heterosexual population. Whites accounted for 59% of the total sample, followed by Latinos (27%), African Americans (10%), Native Americans (2%) and Asians (<1%). This distribution is was similar to general population distribution. Seventeen (17%) of those sampled spoke Spanish as their primary language. One percent (1%) indicated that they were not US citizens. The respondents' ages ranged from 12 to 70. More than half (71%) of the respondents were between 30 and 49 years of age.

Ninety five percent (95%) of the sample reported receiving regular primary health care. Only 12 (5%) individuals reported that their HIV status was known, but they did not seek care. Barriers to not seeking care included depression, apathy, and lack of transportation and lack of health insurance coverage. Among those not in care 7 (58%) were people of color.

2. Socio-Economic Status/Insurance

The survey results on insurance coverage are similar to the national norm, with over 43% of respondents relying on public funding for services. Forty-three percent (43%) reported relying on AHCCCS or AHCCCS/Medicaid. Ryan White CARE Act covered 23% of respondents, and 13% reported using a combination of policies to cover required services. Nine percent (9%) reported having private insurance, 4%

reported they are uninsured, 2% utilized self-pay, and 1% had VA or dependent coverage. Eleven different private physicians were listed with 46% of respondents receiving care outside of McDowell clinic. Another 44% indicated that they received medical care at McDowell clinic or from a physician who works at the clinic. Within sub populations 81% of Spanish-speaking Latinos received Ryan White CARE Act Services versus 15% of Whites.

Fifty-eight percent (58%) of respondents reported a household income between $0 and $9,999. Whites made up 60% of those living at the lowest income level, with people of color making up 47%. Latinos were disproportionately represented among people of color in poverty accounting for 65% of at this income level.

3. Health/HIV/AIDS Status

Sixty seven percent (67%) of those sampled in the survey were HIV positive, compared to 30% with AIDS. Among PLWH, Whites accounted for (55%) of the total HIV population, Latinos made up (33%) of the population, followed by African Americans at (8%). Whites again accounted for the majority of PLWA (64%), African Americans (14%) and Latinos (14%).

Nearly 28% of respondents indicated that they tested positive for HIV outside of Arizona. This may have substantial implications for service utilization and planning. Many people are currently utilizing services, but are not counted in reported surveillance numbers. Seventy-eight percent (78%) of respondents reported that their T cell count was greater than 200, and twenty six (26%) reported it was unknown. Overall, most respondents described their health as good to very good (62%). Only 5% indicated their health was poor. Whites again were over-represented among those who reported poor health, particularly White women. Among women of color only 1 African American woman and no Latino women reported poor health.

4. Geographic Distribution

The following areas by zip code were identified as having the most number of PLWHA:

1) 85014 = 20
2) 85015 = 11
3) 85021 = 10
4) 85012 = 8
5) 85013 = 7

Overall, 45 different zip code areas were represented in the sample, which suggests that consumers are spread out across the Phoenix EMA area. Only one respondent was from Pinal County.

5. Consumer Health Care Information

Ninety percent (90%) of respondents reported that they regularly get healthcare. In contrast eleven percent (11%) of PLWHA who responded to the survey indicated they did not receive services regularly, and were considered not in care. The most common reason for not receiving regular care was that consumers felt "good." Thirty four percent (34%) reported that they received services monthly, and 14% received services weekly. A significant number (60%) did not require hospitalization during the past year. Twenty percent (20%) reported at least one hospitalization for an HIV/AIDS related complication.

Many consumers (35%) reported receiving medical care either immediately or within one month after their diagnosis. However, over 24% indicated that there was a significant delay in the onset of their treatment ranging from 7 months to more than 14 years. Over 20% of those surveyed noted that the delay between diagnosis and treatment was between 5 and 14 years. This suggests that there is a large number of individuals who are not seeking treatment until they are sick. Of the 35 persons who indicated they waited 5-14 years for treatment 25 were white and 10 were people of color.

6. Identified Barriers/Unmet Needs Among PLWHA and not in Care

a. Barriers to primary care among PLWHA in care (see Appendix C for a breakdown of total responses)

Figure 19: Barriers to Services by Subpopulation

White Women

Responses	Number of respondents
Childcare	6
Food at Meetings	3
Gasoline	5
More personal attention	5
No targeting for separated ethnic groups	5
Car repair	5
No barriers	5
Insurance	2
Attitudes	2
Family ignorance of HIV needs	2
Location of services	2
Money	2
Length of time on waiting list	2
Finding correct doctor covered by insurance (referrals)	2
Prompt emergency help	2
Knowing how to get services	3
Transportation	3
Not knowing who you can trust	3
Being notified of events	3
Being a straight single mother	3
Housing	3
No response	6
No comment	1

Latino Women:

Responses	Number of respondents
Transportation	6
More Spanish speaking providers	5
Lack of housing due to legal status	3
Childcare	2
Food with medication	2
No legal I.D./Status in the U.S.	2
Food at meetings	2
Ignorance/Lack of knowledge	2
Fear to access medical services	1
Fear to be deported	1

Financial Help	1
Housing	1
Lack of communication	1
Waiting time	1
No options to become a legal U.S. resident	1
None	2
No response	5

Latino Males

Responses	**Number of Respondents**
Language	7
Not having housing	3
Transportation	5
Undocumented status in the U.S.	3
Did not understand some of the questions	2
Fear of immigration officer (INS)	2
Unable to obtain legal residency in the U.S.	2
Good relationship with doctors	1
Bilingual doctors	1
Give written appointments instead of verbal	1
Less bureaucracy would help	1
Culture clash	1
No knowledgeable personnel	1
Discrimination	1
People at front desk not courteous	1
Legal assistance	1
Permanent insurance	1
Unable to obtain valid I.D.	1
Lack of knowledge about HIV	1
Lack of knowledge on services available	1
Fairness	1
Responsiveness	1
Friendly Behavior	1
Convenient times	1
Locations	1
Better case management for Pinal county	1
No barriers	1
Screening	1
Costs	1
Answering questions	1
Privacy	1
Anonymity	1
Discrimination	1
None	2
No answer to any of the questions	18

African American Females

Responses	Number of respondents
Caring people	2
Knowledge of services/contacts	2
Transportation	2
Food at meetings	2
Childcare	2
Being female	1
Being outspoken	1
Life limitations	1
Counseling services	1
Quick doctor's appointments	1
No response	1

African American Males

Responses	Number of respondents
Rudeness	1
Calls not returned in a timely manner	1
Compassion of doctors	1
Personal mental health	1
Addiction to alcohol	1
Lack of information about AIDS and where to get medical care	1
Ignorance	1
Fear	1
Apathy	1
Mental Health Services	1
General Assistance	1
Transportation	1
Long wait for services	1
Not qualifying for services (too much money)	1
Better hours	1
Letting strangers help them	1
No barriers	1
No response	9

Asian Males

Responses	Number of respondents
Calls taken by answering machines	1
Calls not returned promptly	1
Problems with referrals to other agencies	1

Native Americans

Responses	Number of respondents
No response	2
No barriers	2
Transportation	1

b. Barriers to Primary Care among PLWHA not in care

Figure 20: Barriers to Access to Primary Care Among Those Not In Care

Sub Population	Barriers to receipt of care by sub-populations who know they are HIV positive, but are not in care	Estimated Number of each sup-population who know they are HIV positive, but are not in care	List of service needs for each sub-population who know they are HIV positive, but are not in care
White men who have sex with men	Outpatient medical care not culturally sensitive Breakdown in communication between doctors, hospitals, and service agencies Long waits for appointments Transportation – too many buses to take Takes to long to get a case manager Difficulty accessing the geographic corridor of services Accessibility to testing Individual decision making Bureaucratic requirements Depression/apathy Don't believe in medicines	1058 to 1267	Counseling and mental health services Specialized AHCCCS worker More outpatient medical care More dental service Case managers located at service agencies Education of consumers for informed decision making Formalized advocacy services Emergency financial assistance Legal services Alternative health services Food/Nutritional services
Men of color who have sex with men	Transportation Lack of culturally competent staff Long waits Location and days available Not located in the immediate community	295 to 368	Availability of counseling and testing Follow up for persons who don't show up Dental care Emergency financial assistance Alternative health services Legal assistance

Women of child bearing age	Long waits Services not gender specific Focus on gay men Low priority on women Complexities of being a care giver Fear of repercussions within family	258 to 308	Emergency financial assistance Consistent, available supplies for women Doctors and other personnel who work well with women Services that consider the care taking needs of mothers
IDU (Injection drug users)	Agency staff look down on IDUs Little training on dealing with IDU's Will not take drug therapies which may conflict with drug use Unaware In and out of prison	238 to 273	Existing services with personnel trained to deal with IDUs Shelter Basic needs such as clothing, food, etc.
Substance abusers (other than injection drug users)	Seen as high risk losers Burned out on medicines Individual decision Impaired and not aware of services	Not Available	Existing services with personnel trained to work with this subpopulation
Adolescents (13 – 19)	Focus is on adult services Little or no age specific services Lack of dollars for services	28	Entry to all services before age 18 Aggressive testing in appropriate sites Treatment without parental OK
African Americans	Afraid of being called gay Ebony House is only for drug users Gay focus Not in the community Not culturally competent Hours not convenient	230 to 314	Dental services Alternative health Counseling and mental health services Emergency financial and legal assistance Should be able to get services even when paperwork is in another state

Hispanic/Latinos	Long waits No Spanish speaking personnel Calls not returned Too long to get case manager No attempt to deal with geographic mobility Fear of the government Not enough education regarding treatment	400 to 484	Emergency financial assistance Legal assistance Food and nutritional services Alternative therapies A hotline for all services
Native Americans	Confusion regarding where to go	49 to 97	Need to coordinate with tribes.

c. Service needs among PLWHA in care

Figure 21: Distribution of Services Currently Being Received by Respondents

Services	**Rank**	**Number**
Food Boxes	1	96
Case management	2	90
Mental health services	3	64
No response	4	40
Support Group	5	16
Vitamins	6	8
Dental	7	6
Transportation		2
No services needed		5
Buyer's Club		5
Medications/Medical services		5
Housing		2
Transportation		2
Housekeeping		2
Exercise program		1
Emergency assistance		1
In home care		1

Figure 22: Top Ten Services that Consumers Need (but do not have access to)

	Rank	**Number**
Dental Care	2	48
Complementary/Alternative Therapy	4	36
Counseling/Mental Health Services	5	30
Child Care Services	7	20

Food/Nutritional Services	6	23
Emergency Financial Assistance	1	67
Legal Services	3	41
Funeral Assistance	8	7
No Services Needed	9	5
No Response	-	95
Assistance with Emergency Hospitalization	11	1
Housing for Undocumented	10	4

Figure 23: Suggestions About How Providers can Better Meet the Needs of Consumers

White Females

Responses	**Number of Respondents**
Have a “drop in” center	1
More programs for heterosexuals	1
Provide food	1
More locations and staff	1
Educate insurance providers to refer to correct specialists	1
Provider awareness	1
Keep patient better informed	1
Present care options	1
More support groups for older straight females	1
Assist with job search	1
Funding to help go see family members	1
No response	11
No comment	3

White Males

Responses	Number of Respondents
More information available in bars, doctor's offices, gyms, etc.	4
More funding for case managers	3
Consolidated services/paperwork	3
DES rude	3
Compassion	2
Providers know what services are available	2
Safe sex education, education	2
Raise income for ADAP & ECAP housing	2
Discuss needs	2
Meals and snacks for meetings	2
Insurance covering special equipment	1
Contact with HIV/AIDS long-term survivors	1
City housing quicker service	1
Quick referral for service	1
Group leaders should be same sex	1
Outreach	1
Daycare	1
Better hours for meetings	1
Expand health coverage	1
Car insurance plans	1
Home visits	1
Need more heterosexual men's groups	1
Transportation	1
Increased service	1
Allow veterans to access Ryan White	1
More information on NMD	1
No comment	20
No response	50

Asian Male

Responses	Number of Respondents
Providers need to know clients better	1

Native American Males

Responses	Number of Respondents
Not happy with services	1
I was ignored by Native American Pathways (service provider)	1
No response	3

Latino Females – Spanish Speaking

Responses	Number of Respondents
Less waiting	11
Return messages	1
More doctors who speak Spanish	1
Give good care	1
More advertisement	1
None	2
No response	5

Latino Males – Spanish Speaking

Responses	Number of Respondents
More bilingual case managers	4
More bilingual doctors	5
Reducing waiting time at urgent care	1
Some agencies should give good service	1
Return phone calls	1
People who can understand AIDS	1
Avoid AHCCCS denial to obtain services	1
More publicity	1
Whatever news you can give us	1
None	5
No response	11

Latino Females

Responses	Number of Respondents
Provide food and drink (medications taken at dinner time)	1
Everything is excellent	1
None	2
No response	5

Latino Males

Responses	Number of Respondents
Compassion and listen more	3
Take services outside central Phoenix	2
Dissemination of service information	1
Excellent job	1
Home care	1
Not applicable	5
No response	5

African American Females

Responses	Number of Respondents
Stop segregating by ethnic group	1
More compassion from doctors	1
No comment	1
No response	2

African American Males

Responses	Number of Respondents
Better explanation of medications and side-effects	1
Specific care for people of color	1
Better outreach services	1
Doing great	1
No comment	6
No response	7

Figure 24: Concerns/Suggestions About Health Care in Phoenix EMA

Question: "Do you have other concerns/suggestions about the status of medical services for PLWHA in Maricopa/Pinal County?"

Response Category	Number	Rank
No response	105	
Doing a good job-thank you for your helps excellent services	14	1
Bilingual personnel	4	5
Have additional clinics	1	
More doctors	5	3
Less waiting/referral delays/too long to get services	6	2
Courtesy in personnel	1	
Home health assistance	2	
Early discharge from hospital	1	
Medigap coverage due to legal status in US	1	
More alternative therapy access like acupuncture and counseling	1	
More emergency appointments	1	
Discrimination/Veteran discrimination	2	
Help with insurance	1	
Additional funds for medications	1	
Clinics are understaffed	2	
Not enough services/Lack of funding for programs	5	4
Multiple requests for income verification is frustrating/Time wasted to get denial letter from AHCCCS to stay on Ryan White	3	
Lack of continuity of care	1	
Open information and services should be available to all	3	
Support groups for grief, older straight HIV+ are needed	2	
Need more information about what services are available	2	
Need a gym	1	
Referrals to specialists are difficult to get	2	
Empowerment for proactively should be stressed by ASO's	1	
Housing for homeless is needed	1	
Childcare vouchers needed	1	
New laws governing transmission of virus	1	
Dr. withheld important information	1	
Assistance with job searching is needed.		

Figure 25: Consumer Perception of What Providers Need to Offer in Order to Better Serve the Consumer

Question: "In order to offer better services it is important that HIV/AIDS providers." (Numbers reflect the selection of one or more responses based on its importance to the individual)

	Number	Percent
Providers must be experienced and knowledgeable about providing HIV care	151	23%
Providers must know what HIV-related services are available in Maricopa/Pinal County Areas	134	21%
Providers need to offer services in a more convenient manner	102	15%
Advocate for client needs	97	15%
Providers must know how to work with people from different cultures	83	12%
Providers must know a language other than English	74	11%
Other		
Better office hours	7	
Quicker appointments	21	
Less waiting	20	
Location easier to get to	9	
Problems with DES	1	
Unhappy with McDowell Clinic	1	
Get the facts correct	1	
Have a better understanding of living with HIV	1	
User friendly child care services	3	
Have gas vouchers	1	
Have food at meetings	1	

V. Summary and Results of Provider Interviews and Focus Groups

A. Provider Interviews/Focus Group

1. Assessment of Barriers to Those in Care

Comments presented reflect the opinion of providers and consumers who participated in the interviews. Responses were categorized and the following themes emerged based on interviews with providers and with focus group participants:

a. General Barriers:
- Large increase in demand for primary medical care and other services with no comparable increase in funding
- Breakdown in communication between hospitals, outpatient clinics, and other service providers so that consumers fall through the cracks
- Staff turnover resulting in poorly trained and uninformed staff in hospitals and in agencies
- Not enough testing provided
- Not enough behavioral health services available and/or accessed by consumers
- Children ages 13+ can be tested without parental permission but cannot receive services without parental permission
- Inability to target children and adolescents in the public schools
- Lack of bilingual staff

b. Agency-Related Barriers:
- Competitiveness between agencies. Referrals between agencies limited.
- Location and hours of service availability
- Lack of cultural sensitivity (not limited to Latinos)
- Little or no follow-up of no-shows
- Length of time it takes to get appointments for primary medical care and alternative health care
- T-Cell level needed to receive care (e.g. not sick enough)
- Lack of collaboration
- Overworked case managers and other staff
- Low tolerance of substance abusers
- Lack of training of physicians

c. Consumer-Related Barriers:
- Consumers unaware of choices and services
- Little education available for consumers to make informed decisions
- Substance abuse problems
- Individual forgetfulness

- Lack of transportation-no car, gas money, or bus ride too lengthy
- If working, may not have sick time to visit medical providers
- Individuals chose to not access medical care
- Mothers fear losing children to CPS
- Unwillingness to follow required drug protocol
- Fear of family backlash
- Difficulty in accepting the need to change medical providers
- Lack of sensitivity to women's needs
- Lack of phones, transportation and/or access to the Internet
- Lack of trust towards agencies and medical providers

d. Barriers Related to Bureaucratic Requirements:
    - Need for AHCCCS denial letters (have to make trips to different sites and wait, (which creates additional transportation burden for consumer)
    - Proper ID for undocumented persons (proof of residency)
    - Governmental requirements implemented differently by different agencies
    - Co-pays (money owed) prevents some from continued medical care
    - Do not qualify for AHCCCS and do not want to get services at McDowell Clinic
    - Services in Pinal County do not meet needs

2. Access Barriers to PLWHA Not in Care

The following themes emerged from discussions with focus group participants, some of whom were HIV+, but not in care:

a. General Findings:
    - Lack of information on services available
    - Limited geographic distribution of services
    - Lack of cultural sensitivity
    - Need for legal ID
    - Fear of deportation
    - Highly mobile-not in one place long enough to tap into services
    - Services not accessible
    - Lack of trust
    - Lack of bilingual staff on phone and/or reception
    - AHCCCS denial required every 6 months
    - Transportation problems
    - Substance abuse problems/mental health issues (e.g. depression)
    - Do not want to be identified as having HIV/AIDS
    - Fear of community prejudice against HIV/AIDS
    - Little or no outreach in Pinal County

b. Barriers Identified in Consumer Focus Groups:
    - Lack of networking by the agencies
    - Treated as just another number
    - Hostile staff members
    - Not all testing personnel can do appropriate counseling and referrals for persons who turn out to be positive, thus person may not get to services quickly
    - Lack of knowledge concerning women's special needs
    - Lack of knowledge by agency personnel concerning vitamins which work against AIDS medications
    - Agencies are gay male oriented and do not want to serve women
    - Takes too long to get appointments for alternative health services
    - Not enough funding for services to women
    - Cuts have focused on services/supplies for women
    - Transportation problems
    - Duplication of services
    - Long waits in waiting rooms
    - Length of time it can take to get AHCCCS

VI. Assessment of Service Gaps and Estimates of Unmet Need

Finding people living with HIV/AIDS who are unconnected to services is a challenge, particularly given the rapidly shifting population of the Phoenix EMA and the large number of undocumented persons who do not trust interactions with any formal system in the US for fear of detention and or deportation. By definition, those not in care are a hidden population. A Columbia University study of the unconnected in 1998 found that this population generally was extremely hard to reach even with aggressive street outreach. Characteristics of this population include a multitude of risk factors (e.g., homelessness, chemical addiction, and serious mental illness). The presence of these accumulated risk factors differentiates this population from those who know their status and seek care. There have been few formal efforts to locate and describe the unconnected. However, a recent assessment of people living with HIV/AIDS not in care in Seattle found that people remained outside the service system by choice (Natter, Hopkins & Faricy, 2001). Another recent study, in Miami-Dade County, underscored the difficulty in quantifying this population. A survey of 911 potential HIV individuals targeted in high risk areas yielded only 14 persons who were HIV positive and not in care (Williams, Stern & Associates, Survey of the Unconnected, 2001).

Although the Phoenix EMA offers a broad continuum of care, which according to many consumers is doing a good job meeting their needs, the community is now challenged to define and service those who are not receiving HIV related care, while maintaining or expanding current capacity to meet the needs of those who are in care.

The Health Resources and Services Administration [HRSA] defines the unconnected as those who are not currently receiving HIV-related medical care. This is referred to as an unmet need. While there is no widely accepted definition of unmet need, for the purposes of this assessment unmet need is more narrowly defined as a service need of an individual who knows they are HIV positive, but are not currently in the system of HIV/AIDS care.

The terms “in-care” and “not in care” are also ambiguous in many contexts because there is no agreement about the frequency of types of services that constitute primary care. For the purposes of this assessment they are defined below:

In care-refers to PLWHA who were in receipt of at least one primary medical care service within the past year (alternative medical services would not be included in this definition).

Not in care-refers to PLWHA who are not receiving primary medical care for their HIV in the past year (either through the CARE Act or other services).

In terms of quantifying this population, the Centers for Disease Control suggests that when considering the HIV/AIDS population as a whole, generally one third of the population has HIV/AIDS and is in treatment, one-third is HIV positive but undiagnosed, so they are not seeking care, and the final one-third is aware they are HIV positive, but are not in care (Health Resources and Services Administration//HIV/AIDS Bureau, 2000).

To understand possible reasons why PLWH would not access services, some inferences based on previous research about individuals who remain outside the healthcare system in the general population must be made. The reasons typically identified have included:

- Lack of means to pay for care
- Suspicion of the system
- Personal inability to comply with medical care (for religious/cultural reasons)
- Medical care is necessary only in emergency situations

Other barriers may include:

- Lack of transportation to services
- Lack of knowledge about what services exist
- Having no insurance
- Language or cultural barriers
- Substance abuse
- Mental or other chronic illness which make compliance with regular medical treatment difficult

The quantitative determination of unmet need is guided by the principles set forth by the CDC. The methodology used and other details are noted.

A. Estimate of Unmet Need Based on CDC Estimate of Proportion in Service

Part 1: Recorded Number of People Living with HIV/AIDS Tested in Arizona

Table 1 shows the number of people with HIV or AIDS who are currently living in the Phoenix EMA according to Maricopa County Department of Public Health records. These numbers includes *only* people who were initially tested and reported in the state of Arizona.

Part 2: Percent of Survey Respondents Who Tested Outside of Arizona

To account for in-migration of people living with HIV/AIDS, we conducted further calculations. Table 1 Part 2, presents the percent of people in the 2002 Consumer Survey (documented earlier in this report) who said they were tested in a state other than Arizona. For example, 14% of women in the survey said that they were tested in some state other than Arizona. This means that they would not be included in the recorded number of PLWHA from Part 1.

Part 3: Confidence Interval for Percent Tested Outside Phoenix EMA

A confidence interval was calculated (at the 90% level) to account for the size of the sample and other factors in the survey. A confidence interval reveals the highest and lowest possible values given the information available. For example, this means that between 6% to 22% of all women living with HIV/AIDS in the Phoenix EMA were tested outside of the state. (See Table 1, Part 3.)

Part 4: Adjusted Number of People Living with HIV/AIDS, Accounting for In-Migration

The confidence interval listed in Part 3 was applied to the recorded number PLWHA listed in Part 1 in order to recalculate a number that accounts for in-migration. The end result (shown in Part 4, Table 1) shows the estimated low and high numbers of PLWHA in the Phoenix EMA. For example, we accounted for the 6-22% of women not in the original count and found that between 781 and 996 are probably now living in the EMA. In other words, if there are 781 women with HIV/AIDS in the Phoenix EMA, 6% or 47 women were most likely tested outside of the state.

Please note that these estimates may be inflated somewhat because they account for people who moved *into* the Phoenix EMA, but do not account for out-migration or people who were tested in Arizona and moved away. The reason that out-migration is not included is because these data are not available from any source.

Table 1: Estimate of PLWHA in Phoenix EMA Accounting for In-Migration						
	Part 1: Recorded Number of People Living with HIV/AIDS tested in AZ (MCDPH)	**Part 2: Percent of Survey Respondents Who Tested Outside of Arizona**	Part 3: Confidence Interval for Percent Tested Outside Phoenix EMA		Part 4: Adjusted Number of People Living with HIV/AIDS, Accounting for In-Migration	
			Low	**High**	**Low**	**High**
White MSM	2551	27%	20%	34%	3206	3839
MSM of color	844	15%	6%	24%	894	1116
Women	731	14%	6%	22%	781	933
IDU	722	0%	0%	13%	722	827
Substance abusers (other than IDUs)	na	47%	29%	65%	na	na
Adolescents, age 13-19	84	0%	0%	unknown*	84	84*
African American	667	17%	4%	30%	696	951
Hispanic/Latino	1089	18%	10%	26%	1213	1467
Native American	149	20%	0%	49%	149	295
*Note: Because there was only one adolescent in the survey, it is not possible to calculate a confidence interval for this group. Therefore, for purposes of this report, the adjusted number of adolescents should be considered the same as the reported number = 84.						

Part 5: Estimate of PLWHA in the Phoenix EMA Who are Not In Care

Beginning with the estimates calculated in Parts 1-4, we applied the CDC's estimate for the percentage of people who are not receiving service. The CDC estimates that 33% of PLWHA are not currently in care. Therefore, our best estimate for the number of women in the Phoenix EMA who are not in care is at least 258 women and no more than 308 women (Table 2, below).

Table 2: Estimate of People Living with HIV or AIDS Who are not in Service				
	Adjusted Number of People Living with HIV/AIDS, Accounting for In-Migration (from Table 1, Part 4)		Part 5: Estimate of PLWHA Who Are Not In Care	
	Low	**High**	**Low**	**High**
Subpopulation				
White MSM	3206	3839	1058	1267
MSM of color	894	1116	295	368
Women	781	933	258	308
IDU	722	827	238	273
Substance abusers (other than IDUs)	na	na	na	na
Adolescents, age 13-19	84	84	28	28
African American	696	951	230	314
Hispanic/Latino	1213	1467	400	484
Native American	149	295	49	97

VII. Recommendations for Improved Access to Services, Community Planning/Resource Allocation, Education and Research

The following recommendations emerged based on the extensive review of qualitative and quantitative data:

A. Improved Access to Services

- Eliminate competition - develop a true network of services. This would allow for reducing waste associated with duplication of services and improved access to care.

- Expand services geographically. Residents in East and West Phoenix and in Pinal County would greatly benefit from education and treatment services.

- Need to standardize protocol to educate doctors about when to test for HIV based on historical risk factors (e.g. Ob/Gyn doctor should follow up with testing recommendation for wife when husband is positive.)

- Have an AHCCCS eligibility worker dedicated to HIV/AIDS consumer needs and a well-advertised "hot line" with expert knowledge on all services and requirements for services. Many current consumers have a variety of unmet needs outside of primary care health needs (e.g. emergency financial assistance, burial assistance, and housing).

B. Community Planning/Resource Allocation

- Increase HIV testing opportunities in the Phoenix EMA. CDC Behavioral Risk data indicates that in AZ only 38.5% of individuals have been tested.

- Develop culturally and linguistically competent support services that are consistent with values important to Latinos, Native Americans, and African Americans.

- Access to more support groups for heterosexual PLWHA is needed. Several respondents to the survey noted that consideration should be given to having a site or sites specifically for women and also for heterosexual males.

- Increase primary care services to address co-morbidity, mental health, and substance abuse issues.

- Particular attention should be paid to improving access to medical care categories, particularly dental services and alternative health services.

Survey results indicated that many consumers wanted these services, but did not have access to them.

- Increase efforts like the Women's Volunteer Network, and fund continued efforts to connect with women of color.

- Increase case management support so that when individuals fail to show up for appointments or for medication, follow up can be done. Given the growing number of new cases per year the demand for caseworkers will be significant. The benefits of case management have been well documented. Based on the findings of Shapiro et. al. (2001) PLWHA who had the most intensive contact with their case managers (once or twice per month) was least likely to have unmet needs for home health care, emotional counseling, and other support services. Of the 28,332 HIV infected adults receiving care, 67 percent needed at least on supportive service in addition to medical care. Overall, the study concluded that more frequent contact with a case manager within a six-month period was strongly associated with fewer unmet needs for services (Katz et. al. 2001). In a recent study PLWHA were more likely to be using life-prolonging drugs and reduced patients' unmet need for income assistance and health insurance, home healthcare, and emotional counseling.

- Population trends predict continued growth and projected number of new HIV cases will reach 400 next year. In addition to increase access to medical care PLWHA need a number of supportive services ranging from insurance benefits advocacy, housing to emotional counseling and substance abuse counseling. This was clearly documented in the results of the current survey.

- Support long-term volunteer efforts in the community to ensure that volunteer efforts to provide outreach in the community to those unconnected from support services. A long-term commitment is needed so that trust can be established between the volunteer coalition and the populations at risk.

C. Education

- Expand prevention efforts for young gay men of color and develop an international education coalition to improve education efforts for this population that reside in Mexico. Collaboration between service providers in the Phoenix EMA and other neighboring border regions in the US and Mexico will be needed.

- Expand school based programs and community efforts to reach “out of school” or “alternative school” populations (e.g. juvenile offenders, homeless youth, and foster care youth, runaway youth). If this is considered an epidemic then reform of current curriculum and practices in public schools needs to be considered.

- Comprehensive community-based prevention efforts are needed to increase awareness of the relationship between drug use and sexual transmission of HIV. Adolescents are a subpopulation that should be targeted with this message.

D. Future Research

- Increase provider communication with private physicians and providers about research opportunities regarding clinical trials to make research accessible, particularly to people of color.

- Develop data coordination method between relevant agencies to ensure that estimates of unmet needs are as accurate as possible. Lack of access to data from non-Ryan White CARE Act sources/providers (e.g., AHCCCS/Medicaid, Medicare, private physicians, HMO’s or the VA) hinders the estimation of unmet need. HMO’s do not share information; data about the number of individuals with HIV or AIDS receiving primary care through AHCCCS/Medicaid is very difficult to obtain. McDowell clinic was very cooperative and shared information about use patterns among its current client base. However, even from this data, it is not possible to ascertain what percentage of current clients were receiving services through CARE ACT or other insurance methods.

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IX. Appendices

Appendix – A -1

Survey of People Living with HIV /AIDS
Maricopa and Pinal Counties
2001-2002

Note: all the information you provide will be kept strictly confidential. Your answers are very important to continued funding of Ryan White services in Maricopa and Pinal counties. Please answer all the questions. Fill out only one survey.

The following information will be used as part of a larger study to determine the service needs and to identify barriers to medical treatment for PLWHA in Maricopa and Pinal counties. We need to obtain information about your experiences seeking and receiving medical services—both about the kinds of problems you may have encountered in getting services and about what services you need. Thank you for your contribution.

I. Consumer Background Information-Please check the appropriate box for each question listed below.

1. My current medical status is:

__ I am a person living with HIV
__I am a person living with AIDS
__ I am a parent of a child with HIV/AIDS

2. In general, my health is:

__ Very Good __ Fair
__ Poor __ Good

3. Compared to one year ago, my health is:

__ Better __ About the same __ Worse

4. I am ____ years old.

5. My sexual orientation is:

_ Heterosexual (straight, have sex with people of the opposite sex only)
_ Bisexual (have sex with people of the same sex or opposite sex only)
_ Gay or Lesbian (have sex with people of the same sex only)
_ Other, please specify:_____

6. At home I speak mostly:

__English
__Spanish
__Other (please specify)

7. My racial or ethnic background is:

_African American
_Native American/Alaskan Native
_Asian-Pacific Islander
_Other (please specify)_____
_Hispanic/Latino
_White (non-Hispanic)

8. I am:

_Female
_Male
_Transgender/Transsexual

9. I have the following form of health insurance:

AHCCCS/Medicaid
_Medicare
_Insurance through an employer
_Self-paid insurance
_Dependent Coverage
_ No Insurance
_ I access Ryan White medical services

10. My total household income last year was:

_ $0-$9,999
_ $10,000-$19,000
_ $20,000-$29,999
_ $30,000-$39,999
_ $40,000-$49,999
_ $50,000-$74,000
_ $75,000 or more

11. I am either a US citizen or a legal resident in the US:

_Yes _ No

12. Did you first test HIV positive in Arizona?

_Yes _ No

13. I reside in:

_ Maricopa _ Pinal

14. My zip code area is: _____

II. Consumer Medical Information

1. I go regularly to get medical HIV/AIDS health care _ Yes _ No

If **yes**, please specify where and/or with whom you go get your regular HIV/AIDS health care:

If **yes**, please specify how often you get HIV/AIDS health care:

_weekly
_monthly
_every other month
_every four months
_other (please specify):_____

If you answered **no**, you **do not** go regularly, please explain what your reasons are for not getting regular medical care:

_____
_____

2. I received HIV or AIDS related medical care about _____months/years after I was diagnosed.

3. In the past year how many times have you been hospitalized with an HIV-AIDS related complication for at least one overnight stay?

_ None
_ 1time
_ 2 times
_ 3 times
_ 4 times
_ 5 times
_ 6 times
_ 7 or more times

4. My current T-Cell count is?
_ 200 of less
_ Greater than 200
_ Don't know

5. My current viral load is_____.

6. I can be contacted by my Dr./health care provider by:

_Telephone
_US Mail
_Friend/Family
_Voice mail
_Pager

7. I now am a drug user ____yes ___no

My drug(s) of choice are:_____

8. I used to be a drug user ___yes ___no

My drug(s) of choice were:_____

III. Consumers' Unmet Medical and Related Service Needs

1. I feel that in order to better service persons living with HIV/AIDS providers should: (Please check all that apply).

_ Be experienced/knowledgeable about providing HIV care, such as antiretroviral treatments, dealing with opportunistic infections, and monitoring and explaining my health concerns

_ Know that HIV-related services are available in the Maricopa /Pinal county area and provide referrals to them

_ Provide services in a more convenient manner (such as better office hours, quicker appointments. Less waiting, in a location that is easier to get to?

_ Advocate for my needs within the services system

_ Know how to work with people form other cultures

_ Know a language other than English

_ Other (specify)_____

2. I am currently receiving the following services (case management, food boxes, mental health services, etc.):

3. I need but do not have access to which of the following:

_ Dental Care Services
_ Complementary /Alternative Therapy Services
_ Counseling /Mental Health Services
_ Food/Nutritional Services
_ Child Care Services (e.g. respite care, child day care)
_ Emergency Financial Assistance
_ Legal Services

4. Do you have any other comments/concerns or suggestions about the status of medical services for persons living with HIV/AIDS in Maricopa or Pinal counties?

5. Do you have any comments about how providers can better meet the needs of certain populations living with HIV/AIDS?

6. I think the three significant barriers I faced when trying to get HIV-related services are:

1.
2.
3.

Thank you very much for taking the time to complete this survey.

6/2/02 version

Appendix – A-2

Encuesta para gente con VIH/SIDA

Condado Maricopa y Pinal
2001-2002

Nota: Toda la información que usted provea será guardada estrictamente confidencial. Sus respuestas son muy importantes para continuar recibiendo fondos del programa Ryan White para los servicios que se prestan en los condados Maricopa y Pinal. Por favor responda todas las preguntas.

La siguiente información será usada como parte de un estudio más extenso para determinar las necesidades de servicios y para identificar barreras para obtener tratamiento médico para personas que viven con VIH/SIDA en los condados Maricopa y Pinal. Necesitamos obtener información acerca de sus experiencias cuando ha buscado y recibido servicios médicos. Mencione ambas cosas: Los tipos de problemas que pudo haber encontrado para obtener servicios así como servicios que necesite. Gracias por su contribución.

I. **Antecedentes del consumidor.** Por favor marque las respuestas apropiadas a cada una de las preguntas listadas abajo.

1. Mi estado médico actual es:

? Soy una persona que vive con VIH
? Soy una persona que vive con SIDA
? Soy madre/padre de un niño con VIH/SIDA

2. En general mi salud es:

? Muy buena ? Regular
? Pobre ? Buena

3. En comparación al año pasado, mi salud es:

? Mejor ? Igual ? Peor

4. Mi edad es _____años.

5. Mi orientación sexual es:

? Heterosexual (solamente tengo relaciones sexuales con personas del sexo opuesto)
? Bisexual (tengo relaciones sexuales con hombres y mujeres)
? Homosexual ó lesbiana (sólo tengo relaciones sexuales con personas de mi sexo)
? Otro, por favor especifique:_____

6. En casa generalmente hablamos:

? Inglés
? Español
? Otro(por favor especifique)_____

7. Mi origen étnico ó raza es:

? Africo-americano
? Nativo de América o Alaska
? Asiático/Isleño del Pacífico
? Hispano/Latino
? Blanco (no hispano)
? Otro (por favor especifique)_____

8. Yo soy del sexo:

? Femenino
? Masculino
? Transgénero/Transexual

9. Tengo el siguiente seguro médico:

? AHCCCS
? Medicare
? Seguro médico por medio del trabajo
? Seguro pagado por usted (privado)
? Cobertura médica por ser dependiente (menor/cónyuge)
? No tengo seguro médico
? Uso los servicios de Ryan White

10. Mi ingreso total del año pasado fue:

? $0 - $9,999
? $10,000 - $ 19,999
? $ 20,000 - $ 29,999
? $ 30,000 - $ 39,999
? $ 40,000 - $ 49,999
? $ 50,000 - $ 74,000
? $ 75,0000 ó más

11. Soy ciudadano de los Estados Unidos ó residente legal de los Estados Unidos
__Sí __No

12. Su primer examen positivo del VIH se realizó en Arizona?
__Sí __No

13. Yo resido (vivo) en:
__Maricopa __Pinal

14. Mi código postal es:_____

II. Información médica del consumidor

1. Voy regularmente a obtener cuidado médico para el HIV/SIDA ___Sí ___No

Si su respuesta es **sí,** por favor especifique dónde y/o quién va para su cuidado Médico para VIH/SIDA:
_____
_____

Por favor especifique que tan seguido tiene cuidado médico para el VIH/SIDA:
___Semanalmente
___Mensualmente
___Cada dos meses
___Cada cuatro meses
___Otro (por favor especifique):_____

Si contestó **no,** ó si usted **no va regularmente,** por favor explique sus razones por las que no está recibiendo cuidado médico regularmente.
_____
_____

2. Recibí cuidado médico para el VIH/SIDA aproximadamente ____meses/años después que recibí mi diagnóstico.

3. Durante el año pasado, cuantas veces estuvo hospitalizado –cuando menos una noche- debido a una complicación médica causada por el VIH/SIDA.

___Ninguna
___1 vez
___2 veces
___3 veces
___4 veces
___5 veces
___6 veces
___7 ó más veces

4. Mi conteo actual de células T es?
___200 ó menos
___Mayor de 200
___No sé

5. Mi carga viral actual es _____.

6. Mi doctor o proveedor de servicios médicos se puede comunicar conmigo por:

___Teléfono (en casa)
___Correo
___Teléfono de un amigo/familiar
___Centro de mensajes telefónico
___Pager

7. Actualmente uso drogas ___Sí ___No

8. Anteriormente usaba drogas ___Sí ___No

III. Necesidades médicas y servicios relacionados al VIH/SIDA no recibido por los consumidores.

1. Siento que para dar mejor servicio a las personas que viven con VIH/SIDA los deberían: (Marque todas las opciones que se apliquen).

___Tener experiencia/conocimiento para proveer cuidado relacionado al HIV, tales como: tratamientos antivirales, tratamientos para las enfermedades oportunistas, vigilar mi salud y explicar preguntas que surjan con respecto a mi salud.

___Conocer los servicios relacionados al VIH en los condados Maricopa/Pinal y proveer ayuda para recibir dichos servicios.

Proveer servicios en forma más conveniente, tales como:

___Mejores horas de oficina
___Citas más rápido
___Menor tiempo de espera
___Mejor localidad/ mejor acceso para llegar al consultorio médico
___Como trabajar con personas de otras culturas
___Saber otro idioma/s además de ingles
___Otro (especifique)_____

2. Actualmente estoy recibiendo los siguientes servicios (case management –gerencia de casos-, cajas de comida, servicios de salud mental, etc):
_____
_____

3. Necesito pero no tengo acceso a lo siguiente:
- ___Servicio de cuidado dental
- ___Servicio de terapias complementarias/alternativas
- ___Servicios de salud mental/asesoría psicológica-emocional (consejería)
- ___Servicios de salud y nutrición
- ___Servicio de cuidado infantil (en casa y para asistencia a grupos, citas)
- ___Servicios de ayuda financiera de emergencia
- ___Servicios legales

4. Usted tiene otros comentarios/preguntas ó sugerencia acerca de los servicios médicos para personas que viven con VIH/SIDA en los condados Maricopa ó Pinal?
_____
_____

5. Tiene algún comentario acerca de como los proveedores pueden mejorar los servicios y cubrir las necesidades de ciertas poblaciones que viven con VIH/.SIDA?
_____
_____

6. Considero que las tres barreras más significativas que yo he tenido para obtener servicios relacionados con el VIH son:

1.
2.
3.

Muchas gracias por tomarse el tiempo para participar en esta encuesta.

Appendix – B-1

2002 ASO QUESTIONNAIRE

AGENCY:_____

Person interviewed:_____

Date of visit:__/__/__

Subpopulation(s) discussed:

Total male: total female:

White Men who have sex with men **men of color who have sex with men** **women of child bearing age(13-44)**

Injection drug users **substance abusers (other than injection..)** **Adolescents (13-19)**

African Americans **Hispanic/Latinos** **Alcohol abusers**

What is your agency capacity? How many can you serve? Zip codes served.

Staffing pattern: **Number of bilingual workers:** **Case load size/worker:**

Do you provide services to other counties, especially Pinal? What do you do to be able to provide services in those locations?

What is your utilization at the present time by HIV/AIDS consumers and then specifically by the circled subpopulations (specific figures, staffing patterns:

How do you market your services to the subpopulations circled above?

Are there persons who receive services from your agency who do not access primary health care? Do you keep data on this population? Estimates?

Are there persons who do not want HIV medical care or HIV medications—numbers?

Do you provide alternative health modalities (which ones)? Utilization rates for the different modalities the agency provides:

Do persons seek these out instead of primary medical care or HIV medical care?

Barriers you see for the subpopulation groups circled receiving primary medical care and HIV/AIDS medical care:

In your opinion how available and accessible are primary health care providers and HIV/AIDS medical care to the HIV/AIDS subpopulation circled above:

Describe your working relationship with the primary health care provider(s) (do you refer to them?)

Describe your outreach efforts:

% of HIV tests:

% of people who return for health results

Other types of outreach efforts

Describe your case management activities:

Would you be willing to allow us to administer surveys to a sample of your clients?
(Through the staff or by handing them to clients as they come in with a place to put them)

Appendix – B -2

McDowell Clinic Questionnaire

Services provided (dental, laboratory services, wellness exams, eye exams, naturopathic (alternative), psychiatric, psychologist, counselor, women's care, etc):

Eligibility requirements for services at the Clinic?
% on AHCCCS: % on Ryan White:
% on Medicare: % self pay:

Who do you serve (numbers by subpopulations): (zip code)(county):

	Total male:	Total female:
White men who have sex with men:		
Men of color who have sex with men:		
Women of child-bearing age (13-44):		
Injection drug users:		
Substance abusers (other than injection…):		
Alcohol:		
Adolescents (13-19):		
African Americans:		
Hispanics/Latinos:		
Transgender:		
Other:		

How do you market McDowell Clinic (outreach efforts):

What services other than primary medical care do you provide?

What is your capacity?

What is your volume/day?

Capacity for Urgent Care appointments per day:

How many HIV/AIDS consumers do serve:
HIV:

AIDS:
Frequency of visits (by service):

What do you do to minimize no shows—how do they follow up with those who do not come in for their appointments?

At what point do you consider a consumer no longer active with them.

Do you keep track of the number of persons who may refuse medical treatment?

Do you follow-up with persons who refuse medical treatment?

Barriers you see preventing consumers from getting primary medical care services from them:

How many undocumented consumers do you serve?

How many doctors and other staff are bilingual in Spanish (ratio)(Other languages)?

What other primary medical care facilities serve the HIV/AIDS population:

How do you coordinate/communicate with them?

How do you coordinate services with other agencies serving these consumers? What is the frequency of referrals from the other HIV/AIDS agencies?

Can we come and have people fill out surveys while they wait? Ex: women's clinic.

Can I meet with your counselors/outreach staff and others?

Appendix - C

1. Consumer Demographics

Figure A. Gender

	Number (Total=227)	Percent
Male	170	75%
Female	56	24%
Transgender	1	<1%

Latino Males	17
Latino Males-Spanish Speaking	27
Latino Females	10
Latino Females-Spanish Speaking	12
African American Males	17
African American Females	6
Native American Males	4
Asian Male	1
White Males	104
White Females	28
Native American Transgender Male	1

Figure B. Race/Ethnicity

	Number (Total=227)	Percent
Black/African American	23	10%
Latino	66	27%
Native American	5	2%
White	132	59%
Asian	1	<1%

Figure C. Primary Language

	Number (Total=227)	Percent
English	183	81%
Spanish	39	17%
Other (4 =Eng/Span, 1=Apache)	5	2%

(*Spanish-speaking respondents were all Latino)

Figure D. Age

	Number (Total=214)	Percent
Under 19	1	<1%
20-29	25	12%
30-39	76	35%
40-49	78	36%
50-59	21	8%
60 and over	4	1%
No Response	9	4%

	HM	HMss	HF	HFss	AAM	AAF	AM	NAM	WM	WF
Under 19	0	0	0	0	0	0	0	0	1	0
20-29	1	6	3	4	2	0	0	1	7	1
30-39	8	12	4	5	2	2	0	4	35	4
40-49	6	6	2	2	6	2	0	0	41	13
50-59	1	2	0	0	3	0	1	0	14	0
60-over	0	0	0	1	0	0	0	0	1	2
No response	1	0	0	0	1	2	0	0	5	0

Figure E. Sexual Orientation

	Number (Total=227)	Percent
Heterosexual	81	36%
Bisexual	15	6%
Gay or Lesbian	113	50%
Transgender	1	<1%
No Response	17	7%

	HM	HMss	HF	HFss	AAM	AAF	AM	NAM	WM	WF
Heterosexual	3	15	10	7	7	6	0	0	12	21
Bisexual	2	0	0	0	2	0	0	2	7	2
Gay/Lesbian	11	12	0	0	7	0	1	2	78	2
Other	0	0	0	0	0	0	0	1	0	0
No Response	1	0	1	5	1	0	0	0	7	2

2. Socio-Economic Status/Insurance

Figure F. Insurance Coverage

	Number (Total=224)	Percent
No Insurance	11	5%
Medicare	43	19%
Medicaid/AHCCCS	55	25%
Insurance through Employer	20	9%
Ryan White Care Act	53	24%
Self Pay	6	3%
VA	0	-
Dependent Coverage	3	1%
Combination	31	14%
No Response	2	<1%

	HM	HMss	HF	HFss	AAM	AAF	AM	NAM	WM	WF
No Insurance	0	0	1	0	0	0	0	0	9	1
Medicare	1	1	2	0	4	1	1	1	24	8
AHCCCS/ Medicaid	5	4	4	1	6	3	0	2	23	7
Insurance Employer	5	0	0	0	3	0	0	1	7	4
RWCA	1	19	0	11	1	0	0	0	14	7
Self Pay	1	1	0	0	1	1	0	0	2	0
VA	0	0	0	0	0	0	0	0	0	0
Dependent Coverage	0	0	0	0	1	0	0	0	2	0
Combination	3	2	0	0	2	0	0	0	22	2
No response	0	0	0	0	0	1	0	1	0	0

Figure G. Household Income

	Number (Total=227)	Percent
0-$9,999	112	49%
$10,000-$19,000	64	28%
$20,000-$29,000	18	8%
$30,000-$39,000	8	4%
$40,000-$49,000	6	3%
$50,000-$74,000	4	2%
$75,000 or more	2	<1%
No Response	13	6%

	HM	HMss	HF	HFss	AAM	AAF	AM	NAM	WM	WF
0-$,9999	6	13	8	11	9	1	0	4	51	9
$10,000-$19,000	6	6	3	0	3	3	1	1	31	10
$20,000-$29,000	2	2	0	0	1	1	0	0	7	5
$30,000-$39,000	2	1	0	0	1	0	0	0	4	0
$40,000-$49,000	0	0	0	0	1	0	0	0	2	3
$50,000-$74,000	1	0	0	0	1	0	0	0	2	0
$75,000 or more	0	0	0	0	0	0	0	0	2	0
No Response	0	5	0	1	1	1	0	0	5	0

3. Health/HIV/AIDS Status

Figure H. Health Status HIV/AIDS

	Number (Total=227)	Percent
HIV	153	67%
AIDS	68	30%
Parent of a Child with HIV	5	2%
No Response	1	<1%

	HM	HMss	HF	HFss	AAM	AAF	AM	NAM	WM	WF
HIV	11	25	6	10	11	2	1	2	64	21
AIDS	6	2	3	0	6	4	0	3	39	5
Parent of a Child with HIV	0	0	2	0	0	0	0	0	1	2
No Response	0	0	0	1	0	0	0	0	0	0

Figure I. Tested Positive in Arizona

	Number (Total=225)	Percent
Tested Positive in AZ	160	71%
Test Positive Other Than AZ	64	27%
No Response	1	<1%

	HM	HMss	HF	HFss	AAM	AAF	AM	NAM	WM	WF
Tested Positive in AZ	15	18	10	11	13	5	1	4	66	21
Tested Positive Other Than AZ	2	8	1	1	4	1	0	1	38	4

Figure J. T-Cell Count

	Number (Total=224)	Percent
200 or Less	53	24%
Greater Than 200	120	54%
Don't Know	48	21%
No Response	3	1%

	HM	HMss	HF	HFss	AAM	AAF	AM	NAM	WM	WF
200 or Less	4	2	2	3	8	2	0	2	22	8
Greater Than 200	9	14	2	2	6	3	1	2	65	16
Don't Know	3	11	5	6	2	1	0	1	16	3
No Response	1	0	0	0	1	0	0	0	1	0

Figure K. Respondents Current Health

	Number (Total=227)	Percent
Very Good	70	31%
Good	74	33%
Fair	69	30%
Poor	14	6%

	HM	HMss	HF	HFss	AAM	AAF	AM	NAM	WM	WF
Very Good	6	8	6	7	4	2	0	1	27	9
Good	5	5	3	3	9	1	1	2	38	7
Fair	5	14	1	2	4	1	0	1	33	8
Poor	1	0	1	0	0	2	0	1	5	4

4. Geographic Distribution

Figure L. Frequency Distribution of Respondents by Zip Code
(* Denotes top 5)

Zip	Number	Zip	Number	Zip	Number
85001	1	85031	1	85302	2
85003	1	85032	4	85303	3
85004	6	85034	1	85304	1
85006	6	85035	2	85382	2
85007	2	85037	1	85335	1
85008	3	85740	1	85355	1
85009	1	85041	1	83735	1
85012	8*	85044	1		
85013	7*	85050	3		
85014	20*	85051	2		
85015	11*	85202	3		
85016	5	85204	2		
85017	4	85213	1		
85018	2	85214	2		
85019	2	85224	1		

85020	3	85228	1		
85021	10*	85280	1		
85022	1	85281	1		
85023	3	85282	3		
85029	1	85301	2		

5. Consumers Health Care Information

Figure M. PLWHA Who Receive Regular Health Care

	Number (Total=223)	**Percent**
Yes	213	95%
No	12	5%

	HM	**HMss**	**HF**	**HFss**	**AAM**	**AAF**	**AM**	**NAM**	**WM**	**WF**
Yes	17	25	7	10	15	4	1	4	95	25
No	0	2	1	0	2	1	0	1	6	0

Figure N. Range of Providers of HIV Related Medical Care

	Number (Total N=150)
McDowell Clinic	48
Dr. Cunningham	13
Dr. Vanig	10
Medical Dr.	7
Dr. Post	8
Phx. Shanti, APAZ	10
Dr. Clark	4
Dr. Fisher	8
Dr. Jimmy	1
Cigna	2
Dr. Paul Kelley	2
Spectrum Medical Clinic	4
VA Hospital (Faust)	7
Dr. Jon	2
AHCCCS	1
Dr. Kuberski	2
Dr. Bhatka	1
Phoenix Children's Hospital	1
Dr. Redenius	1
Dr. Martin	7
Phoenix Indian Medical Center	2
Dr. Culp	4
Dr. Williams (F. P. N.)	1

Dr. Battersby	1
Dr. Robinson	1
Humana Care	1
No Response	19
Does not attend	1

Figure O. Frequency of Medical Care

	Number (Total=215)	**Percent**
Weekly	29	14%
Monthly	72	34%
Every other month	37	17%
Every 3-four months	59	27%
Other (e.g., as needed, every three weeks, every three months, etc.)	11	5%
No response	7	3%

	HM	**HMss**	**HF**	**HFss**	**AAM**	**AAF**	**AM**	**NAM**	**WM**	**WF**
Weekly	1	1	1	0	0	0	0	0	20	6
Monthly	7	11	1	3	7	4	0	2	29	7
Every other month	2	6	2	0	4	1	1	0	19	2
Every 3-four months	6	6	3	6	4	0	0	0	25	9
Other: As needed Every three weeks Every three months Every six months	0	1	0	2	0	0	0	2	3	3
No response	2	1	3	1	0	0	0	0	0	0

Figure P. Number of Hospitalizations for an HIV Related Complication

	Number (Total=226)	**Percent**
None	154	68%
1	31	14%
2	18	8%
3	11	4%
4 or more	8	4%
No Response	4	2%

	HM	HMss	HF	HFss	AAM	AAF	AM	NAM	WM	WF
None	11	19	9	8	12	4	1	2	70	18
1	3	3	0	1	3	1	0	3	13	4
2	0	3	0	0	3	0	0	0	3	2
3	0	3	0	0	3	0	0	0	3	2
4 or more	0	1	0	0	0	0	0	0	6	1
No Response	0	1	1	0	0	1	0	0	1	0

Figure Q. Time between Diagnosis and Health Care Received

	Number (Total=217)	Percent
Immediately	10	5%
2 weeks-1 months	76	35%
2-3 months	33	15%
4-6 months	16	7%
7months-1 year	5	2%
2-3 years	8	4%
More than 5 years (range 5-14 yrs)	29	20%
Other	4	2%
No Response	36	17%

	HM	HMss	HF	HFss	AAM	AAF	AM	NAM	WM	WF
Immediately	0	3	0	0	1	0	0	0	6	1
2 weeks-1 month	6	4	3	3	8	2	1	1	35	13
2-3 months	3	7	0	1	0	0	0	2	16	4
4-6 months	1	1	1	3	2	1	0	0	6	1
7months-1 year	1	0	1	0	0	0	0	0	3	0
2-3 years	0	0	1	1	1	0	0	0	5	0
More than 5 years (range 5-14 yrs)	4	1	2	1	2	1	0	0	14	4
Other	0	1	0	0	0	0	0	0	2	1
No Response	2	6	1	3	0	1	0	2	14	7

Figure R. Drug Use Status

	Number (Total=307)	Percent
Currently a drug user	21	7%
Formerly a drug user	87	28%
Not a drug user	188	61%
No Response	11	4%

	HM	HMss	HF	HFss	AAM	AAF	AM	NAM	WM	WF
Currently a drug user	2	1	0	0	1	0	0	0	17	0
Formerly a drug user	4	6	1	0	9	2	0	4	52	9
Not a drug user	13	24	8	10	15	5	1	5	80	27
No Response	0	1	0	1	1	0	0	0	7	1